4M Network

4M: My health,
My choice,
My child,
My life

INFANT FEEDING FOR WOMEN LIVING WITH HIV

4M Mentor Mothers Network CIC and Salamander Trust

POSITION PAPER, AUGUST 2020

Some healthcare professionals have difficulty supporting HIV positive women who breast feed because they are fearful of the risk of transmission.

You can only make good choices and well-informed choices if you are given all the right non-judgmental info in the first place. In most cases women aren't getting this.

Every woman needs to be supported by her healthcare providers as well as by her partner, so that if for any reason the baby does acquire HIV s/he is brought up to know that her/his mother had every best intention of doing the best thing for her baby.

Summary

This paper was written by women living with HIV who are Mentor Mothers, supporting other women living with HIV before, during and after pregnancy. It has been written on the basis of the collective experiences of Mentor Mothers, and is designed primarily for use by women living with HIV across the UK who may be considering options for feeding their baby. It is also designed for those who support each woman: such as a mentor mother, an HIV clinician, midwife, health visitor, GP, social worker – and ideally her partner and other family members also.

For many women, the decisions we make around infant feeding can feel fraught with difficulties and judgements from others. For women living with HIV, these decisions can feel even more complicated, and it can be very confusing to realise that different advice is given in different countries. In this paper we lay out some of the key international and UK guidelines and research on infant feeding for women living with HIV, to help with making a decision about breastfeeding, formula feeding or a combination of both.

While the current UK pregnancy guidelines still recommend formula feed as the preferred form of infant feeding for babies of women living with HIV, the guidelines also state that any woman wishing to breastfeed should be supported to do so. We set out many of the pros and cons of breast feeding as well as those of formula feed.

We hope that this policy statement will support healthcare workers and women living with HIV alike to move closer to what women really want. This should be based on non-judgmental fully informed, choice; and full support for whatever each woman decides for herself, for each pregnancy, whatever the long-term outcomes may be, both for herself and for each of her children.

We conclude by stating:

"Deciding what route to take with infant feeding is only the first step. All infant feeding, whichever form it takes, can be stressful to begin with, especially for first-time mothers. Whatever each woman decides for herself, she needs full ongoing support from all those around her, so that she feels confident to do what she feels is best for her baby, and so that she and those around her can access the guidance, reassurance and practical support that she needs to maximise her experience of childbirth as a positive, life-enriching experience for herself as well as her baby. 4M Mentor Mothers Network will be looking shortly at practical next steps to take, to strengthen support for the mentees in their care around all infant feeding practices."

Introduction

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The recent history of HIV, pregnancy and infant feeding

Scientific advances over the years have transformed the lives of many women living with HIV and their partners. Whilst a whole generation of women living with HIV either dared not have children or lost them to AIDS-related illness, the younger generation are now able to have babies who are born HIV-free through normal vaginal delivery, provided they are given the right care, respect and support to be able to adhere well to their anti-retroviral treatment (ARV or ART). Being able to take ARV treatment effectively (called adherence) enables a woman to have an undetectable viral load. This means that she is well; that she can conceive through unprotected sex; that she can have a normal vaginal birth; and that the virus cannot be passed on to the baby.

Not all women will be able to adhere fully during pregnancy. However, most can: in the UK 2-3 per 1,000 babies born to women living with HIV were themselves born with HIV in 2016[1]. At present there are about 900 births a year to women living with HIV in the UK, so it is a wonderful advance. The final 'frontier' of these advances is clinicians' perspectives on breastfeeding by women living with HIV in high income countries. This leaflet explains what the issues around this are and our perspectives as women living with HIV who are members of the 4M peer mentor mothers network across the UK.

U=U and infant feeding

The term U=U means Undetectable = Untransmittable, which means that HIV can not be transmitted when a person is adhering to antiretroviral treatment (ARV or ART) and the HIV becomes controlled (undetectable) because of the treatment. However, some uncertainty remains amongst health professionals over the question of whether or not U=U applies to breastfeeding also. Is breastfeeding (with all its other benefits) safe, in terms of HIV acquisition, for babies? The WHO Consolidated Guideline on sexual and reproductive health and rights (SRHR) of women living with HIV recommends that women living with HIV should be supported to breastfeed[2], making it clear that the multiple advantages for the woman and her baby outweigh the potential for HIV transmission when compared to potential diarrhoeal disease through unsterile formula feed preparation, or other potential negative outcomes for babies who are bottle-fed[3].

Different advice in different countries

Even though the WHO Guideline recommends supporting women to breastfeed, HIV clinicians in some high-income countries have expressed concern over whether breastfeeding is the best recommendation for women in their care. This is due to

1 See UCL Great Ormond Street Institute of Child Health, January 2020, Obstetric and paediatric HIV surveillance data from the UK, Population, Policy and Practice Research and Training Department, https://www.ucl.ac.uk/nshpc/sites/nshpc/files/isoss_slides_january_2020.pdf slide 11.

2 WHO, 2017 Consolidated Guideline on SRHR of women living with HIV, http://apps.who.int/iris/bitstream/10665/254885/1/9789241549998-eng.pdf?ua=1

3 See, for example, National Health Service, March 2020, Benefits of Breastfeeding: Your pregnancy and baby guide, website, https://www.nhs.uk/conditions/pregnancy-and-baby/benefits-breastfeeding/

the risk of transmission being small but not zero, and is based on the thinking that accessing formula and creating the sterile conditions needed for formula feed preparation may be less challenging in high-income settings.

This position paper sets out the current views of the 4M Mentor Mothers Network, on the basis of our own perspectives and experiences in the UK.

Who says what now?

What does the World Health Organization Guideline say?

The World Health Organization's (WHO) and UNICEF's 2016 guideline[4] makes the following recommendations and statements:

"Mothers living with HIV should breastfeed for at least 12 months and may continue breast-feeding for up to 24 months or longer (similar to the general population) while being fully sup-ported for ART adherence (see the WHO Con-solidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection for interventions to optimize adherence)." (Recommendation 1)

This was framed by the following statement:

"In settings where health services provide and support lifelong ART, including adherence counselling, and promote and support breastfeeding among women living with HIV, the duration of breastfeeding should not be restricted.

"Mothers known to be HIV-infected[5] should be provided with lifelong antiretroviral therapy or antiretroviral prophylaxis interventions to reduce HIV transmission through breastfeeding.

"Breastfeeding should then only stop once a nutritionally adequate and safe diet without breast milk can be provided."

"National and local health authorities should actively coordinate and implement services in health facilities and activities in workplaces, communities and homes to protect, promote and support breastfeeding among women living with HIV." (Recommendation 2)

"National or sub-national health authorities should decide whether health services will principally counsel mothers known to be HIV-infected to either breastfeed and take antiretrovirals, or, avoid all breastfeeding..." (Principle, Table 3)

"In settings where national authorities have decided that the maternal and child health services will principally promote and support breastfeeding and antiretroviral interventions as the strategy that will most likely give infants born to mothers known to be HIV-infected the greatest chance of HIV-free survival: Mothers known to be HIV-infected (and whose infants are HIV uninfected or of unknown HIV status) should exclusively breastfeed their infants for the first six months of life, introducing appropriate complementary foods thereafter, and continue breastfeeding for the first 12 months of life." (Box, page 28 – from WHO 2010 b)

"Mothers living with HIV and health-care workers can be reassured that ARV treatment reduces the risk of postnatal HIV transmission in the context of mixed feeding. Although exclusive breastfeeding is recommended, practising mixed feeding is not a reason to stop breastfeeding in the presence of ARV drugs.... Justification: The Guideline Development Group unanimously agreed that this should not be a recommendation but instead should be presented as a guiding practice statement. Although the Guideline Development Group was confident of the efficacy of ARV drugs in

4 WHO and UNICEF, 2016, Updates on HIV and Infant Feeding, https://apps.who.int/iris/bitstream/handle/10665/246260/9789241549707-eng.pdf?sequence=1

5 NB we prefer the term "living with HIV" instead of 'infected". See eg UNAIDS, 2015, Terminology Guidelines, https://www.unaids.org/sites/default/files/media_asset/2015_terminology_guidelines_en.pdf

reducing postnatal transmission even when mothers living with HIV are mixed feeding, the importance and value of exclusive breast-feeding for non-HIV-related health outcomes is such that no recommendation should be perceived as endorsing non-exclusive breast-feeding of infants in the first six months of life. However, the group considered that it is equally important to clarify the efficacy of ARV drugs in reducing postnatal HIV transmission even when mothers are mixed feeding and that, although not optimal, mixed feeding while the mother is taking ART is better than not breast-feeding at all." ***(Guiding practice statement 1)***

In addition, WHO's Consolidated Guideline on sexual and reproductive health and rights (SRHR) of women living with HIV[2] (2017) provides guidance on how to overcome barriers to achieving SRHR at the individ-ual, interpersonal, community, societal and policy levels. It promotes strategies, especially those that are peer-led, working in partnership with health and social care providers, to meet women's priorities and enable our comprehensive sexual and repro-ductive health and rights.

In reflection of the 2017 Guideline, WHO's 2019 ARV[6] update states:
"A human rights-based approach to ART: All ART should be prescribed using a human rights-based approach. This means that women of childbear-ing potential or any pregnant or breastfeeding woman receives full information about risks and benefits of ART and medical guidance that is appropriate to her situation and is supported in making voluntary choices around medical therapy initiation, continuation and adherence/retention in care, as applicable. Health workers must help women to appropriately address their health-care needs and those of their children."

What does The British HIV Association (BHIVA) say?

The British HIV Association (BHIVA) pregnancy guideline states:

"9.4 …..Factors that increase the risk of HIV transmission via breast milk when women are not on HIV treatment include: detectable HIV viral load; advanced maternal HIV disease; longer duration of breastfeeding; breast and nipple infection/inflammation; infant mouth or gut infection/inflammation; mixed feeding, in particular solid food given to infants less than 2 months of age.

"9.4.1 In the UK and other high-income settings, the safest[7] way to feed infants born to women with HIV is with formula milk, as there is no on-going risk of HIV exposure after birth. We therefore continue to recommend that women living with HIV feed their babies with formula milk (but also see Section 9.4.4).

"9.4.3 Women who formula feed their infants should be offered cabergoline to suppress lactation.

"9.4.4 Women who are virologically suppressed on cART with good adherence and who choose to breastfeed should be supported to do so, but should be informed about the low risk of transmission of HIV through breastfeeding in this situation and the requirement for extra maternal and infant clinical monitoring"[8].

Although the BHIVA pregnancy guideline does not yet recommend breastfeeding as the preferred feeding option, it makes it clear that it is the woman's right to make her own informed *choice* around whether to breastfeed or not, and that she should be supported by her healthcare providers in whatever choice she makes.

Unfortunately, COVID-19 lockdown restrictions have meant that BHIVA has re-emphasised formula feed as the preferred choice, because of challenges with women accessing ongoing clinical testing:

"Breastfeeding should be discouraged as it requires monthly maternal and infant viral load follow-up for the duration of the breastfeeding period and for 2 months post-cessation of breastfeeding"[9].

6 WHO, 2019, **Update of Recommendations on first- and second-line antiretroviral regimens**, https://www.who.int/publications/i/item/update-of-recommendations-on-first--and-second-line-antiretroviral-regimens
7 Here, "safest" refers to HIV transmission, not overall health, morbidity and mortality.
8 British HIV Association, 2019, **British HIV Association guidelines for the management of HIV in pregnancy and postpartum**, (second interim update), https://www.bhiva.org/file/5bfd30be95deb/BHIVA-guidelines-for-the-management-of-HIV-in-pregnancy.pdf
9 BHIVA, March 2020, **BHIVA statement on management of a pregnant woman living with HIV and infant testing during Coronavirus (COVID-19)**, https://www.bhiva.org/management-of-a-woman-living-with-HIV-while-pregnant-during-Coronavirus-COVID-19

Please see our response to this on page 10 below.

"…as with any 'real world' medical scenarios we are dealing with people and not machines and there is so much variability built into the system" ***HIV Consultant***

"I still find it difficult to understand why women in Low Income Countries (LICs) are advised to breastfeed and we aren't here. They are concerned about the risks of all those infantile diseases but they aren't concerned about it here. If you still think there's a risk, why are you advising breastfeeding in LICs? They make it look as if women don't care about our children as much as we do." ***Extract from Mentor Mothers' discussion about infant feeding***

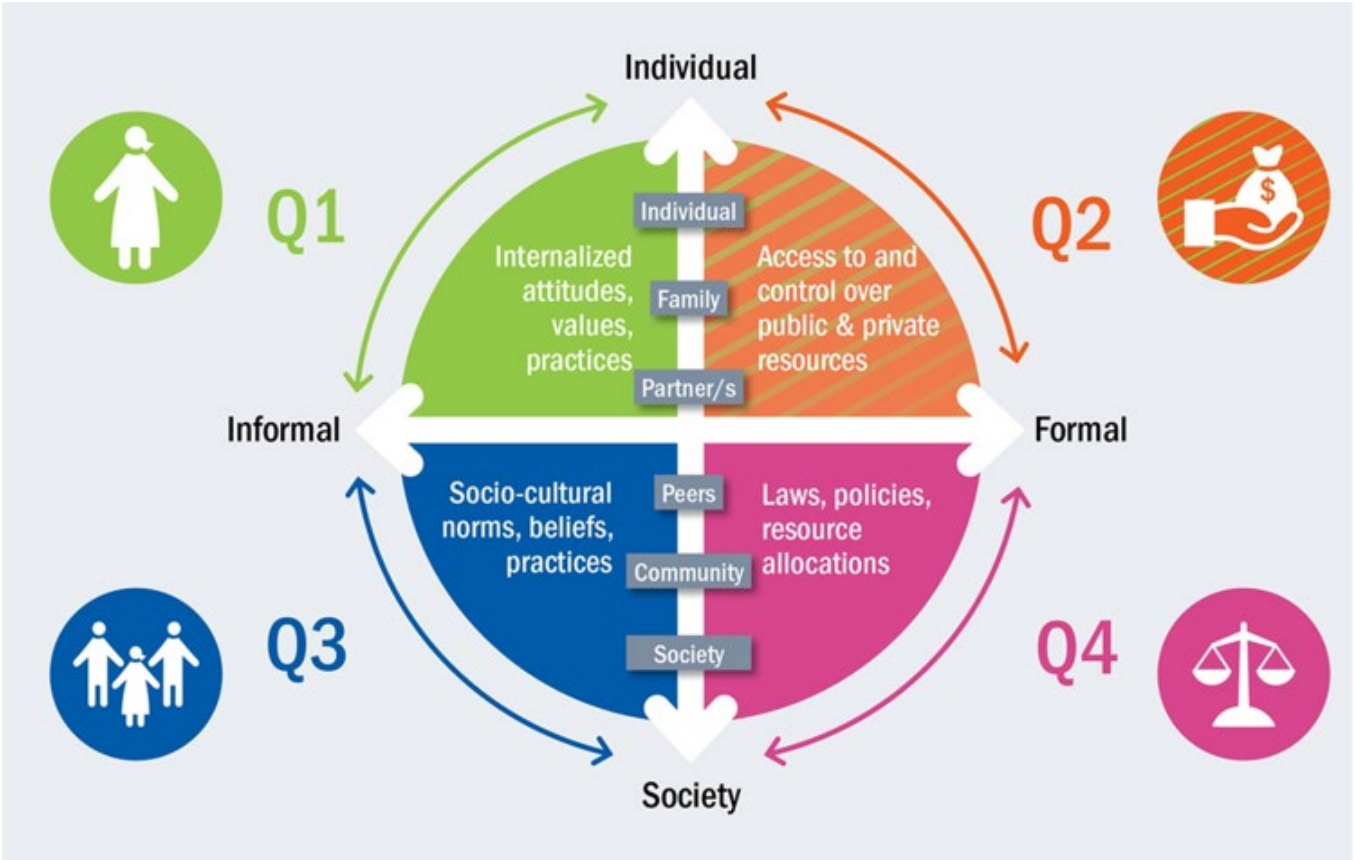
What does the UK National Health Service (NHS) say?

The National Health Service makes it clear that normally for all women and their babies, breast is best[2].

What do we at 4M Mentor Mothers Network say?

Infant feeding for *any* woman is a complex issue, involving physiological, psycho-social and emotional processes, both for the woman and for her baby. Deciding whether or not to breastfeed can be affected by personal emotions, feelings and thoughts about the issue in relation to her own identity as a woman (Quadrant 1 below); the feelings of the woman's partner; her own family; her in-laws; her friends; and neighbours (Quadrant 3 below). It can also be affected by her workplace context; by health workers; and social workers (Quadrant 2 below). When it comes to infant feeding, it can often feel to a woman like everyone owns her body and has the right to tell her what she should or shouldn't be doing with it! In the case of HIV (and some other contexts), the decision can also be affected by the criminal justice system; and by a country's national laws and policies (Quadrant 4 below). Infant feeding is indeed a complex business.

Figure: some of the factors that can influence a woman's choices around breastfeeding, before HIV is even introduced into the mix (Salamander Trust et al, 2017, ALIV[H]E Framework, UNAIDS). https://www.unaids.org/en/resources/documents/2017/ALIVHE_Framework



Ultimately, it should be every individual woman's right to decide whether or not she wants to breast-feed and to be offered full non-judgmental information and support to make her own informed decision.

"Some healthcare professionals have difficulty supporting HIV positive women who breast feed because they are fearful of the risk of transmission." ***HIV consultant***

"One paediatrician who works with teenagers living with HIV told us a couple of years ago that she thought any woman who breastfeeds is really selfish. We thought this is so unfair – both on the teenagers, to be receiving that attitude about their mothers from their clinician, and on their mothers. A paediatrician's role should be to do her best to support all the household members to live positively with HIV in the family, and to be building bridges of understanding between them all, not to be fuelling that sort of blame culture. This reminded us of all the cruel shaming that has gone on for centuries around women who had to give up their children to adoption and the damaging effects on their children who were brought up to reject and feel angry about their birth mothers. On top of that, in the adoption context as in the HIV one, there's barely any mention of the father's part in it all. This also shows how much women continue to be blamed for whatever has 'gone wrong' in a family, by people who should be supporting them. Every woman needs to be supported by her healthcare providers as well as by her partner, so that if for any reason the baby does acquire HIV s/he is brought up to know that her/his mother had every best intention of doing the best thing for her baby." ***Extract from Mentor Mothers' discussion about infant feeding***

What about dads?

It is really important, wherever possible, for a baby's father – or for the intimate partner of the woman – to be involved in parenting as soon as possible also, in order for good bonding to take place between the baby and both parents. This involves policy changes, to ensure that employers and employment law (seen Quadrants 2 and 4 above) give fathers and/or other significant others time off also[10]. And it involves changes in social norms too (Quadrant 3), so that it becomes the norm for fathers to play a positive active and more engaged role in their children's upbringing. Bonding can be done through a variety of ways, such as cuddling, changing nappies, bathing, massaging, reading picture books and taking the baby for walks[11].

The father or other partner can also bottle feed the baby[12]. If the woman would like it, this can be with her expressed breast milk. In the first six months, this should ideally *only* be with the mother's expressed breastmilk which can be chilled or frozen, then rewarmed and bottle-fed to the baby[13] (but see WHO guidance above).

Some hospitals may also still be able to offer women 'flash' heat treating services if they want it, so that their breastmilk has been pasteurised – which is another way of ensuring that no HIV is active in the milk[14].

10 Maternity Action, March 2019, **Rights at work for fathers and partners**, webpage, https://maternityaction.org.uk/advice/rights-at-work-for-fathers-and-partners/

11 National Childbirth Trust, May 2019, **How can dads bond with their babies?** https://www.nct.org.uk/life-parent/bonding-and-caring-for-your-baby/how-can-dads-bond-their-baby

12 Medela, 2019, **Does bottle feeding really promote bonding with dad?**, webpage, https://www.medela.com.au/breastfeeding/blog/preparing-for-breastfeeding/bottle-feeding-really-promote-bonding-dad

13 Mayo Clinic, April 2020, **Breast milk storage: Do's and don'ts**, https://www.mayoclinic.org/healthy-lifestyle/infant-and-toddler-health/in-depth/breast-milk-storage/art-20046350

14 The Well Project, June 2020, **Can I Breastfeed While Living With HIV? An Overview of Infant Feeding Options**, https://www.thewellproject.org/hiv-information/can-i-breastfeed-while-living-hiv-overview-infant-feeding-options

Some key facts

Both breastfeeding and infant feeding have pros and cons. As mothers, we always want to do what is best for our babies and can often feel guilty when we make any decision, because we wonder whether it is the best one. The aim of this resource is to assist a mother with the information to make informed choices and not to make her feel guilty about her choices. Ultimately, every individual is different and has a right to choose. We trust and respect the mother's choice as a fundamental human right, regardless of the method chosen for infant feeding. Every woman should be supported in her choices.

Biological benefits of breastfeeding to the woman and her baby

Benefits for the woman during lactation

- Initiating breastfeeding soon after delivery, and increased frequency of breast-feeding can decrease blood loss during the fourth stage of labour[15].
- Breastfeeding also provides some protection against breast cancer, improves birth spacing, and might also protect against ovarian cancer and type 2 diabetes for the mother[16].
- Breastfeeding releases oxytocin in the woman's body – a hormone associated with relaxation, bonding, trust and love[17].

Nutritional and longer term benefits for the baby

> *"Breastfeeding provides optimal nutrition for the healthy growth of infants and is associated with reduced risks of infectious diseases, child and adult obesity, type 2 diabetes, and other chronic diseases."*[18]

Bonding benefits for the baby

It is still not entirely clear how breastfeeding improves bonding between a woman and her baby[19]. However, skin to skin contact is definitely seen as a positive element, which women who choose not to breastfeed, or who can't breastfeed (as well as their intimate partners) can also practise with their baby[20]. (Skin to skin contact is increasingly recognised as something significantly important for babies born prematurely[21] also).

Benefits of formula feeding in the UK

- Breastfeeding can be really hard for some women to begin with, and if the baby is not gaining weight it can be worrying and guilt-inducing.
- Formula feeding allows partners and others to share feeding responsibilities.

Some challenges of formula feeding in the UK

The NHS Guide on the benefits of breastfeeding[2] states:

"Myth: 'Formula milk is basically the same as breast milk.'

15 Sobhy SI, Mohame NA., 2004, *The effect of early initiation of breast feeding on the amount of vaginal blood loss during the fourth stage of labor.* **J Egypt Public Health Assoc**., 79:1. https://pubmed.ncbi.nlm.nih.gov/16916046/

16 Victora, C.G., et al., 2016, *Breastfeeding in the 21st century: epidemiology, mechanisms, and lifelong effect*. **Lancet**, 387(10017), https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)01024-7/fulltext

17 Matsunaga M, et al, 2020, *Breastfeeding dynamically changes endogenous oxytocin levels and emotion recognition in mothers* **Royal Society Biology Letters**, https://royalsocietypublishing.org/doi/10.1098/rsbl.2020.0139

18 Odeniyi AO, Embleton N, Ngongalah L, Akor W, Rankin J., 2020, *Breastfeeding beliefs and experiences of African immigrant mothers in high-income countries: A systematic review*. **Matern Child Nutr**. 16(3):e12970. doi:10.1111/mcn.12970 https://pubmed.ncbi.nlm.nih.gov/32141195/

19 Hairston, I.S., Handelzalts, J.E., Lehman-Inbar, T. et al., 2019, *Mother-infant bonding is not associated with feeding type: a community study sample*. **BMC Pregnancy Childbirth 19**, 125 https://doi.org/10.1186/s12884-019-2264-0 https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-019-2264-0

20 Norholt H, 2020, *Revisiting the roots of attachment: A review of the biological and psychological effects of maternal skin-to-skin contact and carrying of full-term infants*, **Infant behaviour and development**, 60, https://www.sciencedirect.com/science/article/abs/pii/S0163638319301663

21 Tommy's, 2017, **Kangaroo care**, webpage, https://www.tommys.org/pregnancy-information/pregnancy-complications/premature-birth/your-babys-time-hospital/kangaroo-care

"**Fact:** Almost all formula milk is made from cows' milk. It can contain bacteria, which is why it's vital to make it up with water that is hot enough to kill any bacteria (70°C). It does not protect your baby from infections and diseases like breast milk does."

Unfortunately, many formula milk manufacturers want us to believe otherwise[22].

Cost of not breastfeeding to the mother and baby

Although most mothers involved in a study chose not to breastfeed, to minimise vertical [HIV] transmission risk, it came at a cost. Social pressure to breast feed continues to exist for some women. This is due to the cultural importance of breastfeeding in African communities, concerns about the physical and psychological effects of replacement feeding on their babies, questioning their ability as good mothers and the fear that replacement feeding would indicate an HIV status[23]. There are also financial cost implications for women who find themselves in situations where they are unable to work or have no recourse to public funds. A Canadian study (2019) found an estimated saving of $Can 13,812 (about £8,000) for women living with HIV who breastfed their baby[24].

***"Stigma is sadly a huge part of most HIV positive women's lives and for many bottle feeding can increase that feeling of being different"* HIV Consultant**

Access to formula milk for mothers living with HIV in the UK

"Some mothers living with HIV especially those with irregular migration status, no recourse to public funds (NRPF) and those on low income cannot afford formula milk. This forces them to go hungry, to then be able to afford formula milk for their babies; potentially compromising their own health and HIV treatment effectiveness[25].

- The BHIVA guidelines recommend that *"Women advised not to breastfeed for their baby's health should be provided with free formula feed to minimise vertical transmission of HIV"*[8]
- In addition, a UK study found that women developed more resilience (to adapt and cope with their infant feeding decisions, as well as with those who queried their decision) by receiving financial assistance with replacement feeding, having positive role models of healthy formula-fed children and receiving support from professionals and the community[23].

Potential long-term health challenges of formula feed

A 2016 review stated: "*Factors in utero, early postnatal life and throughout childhood, have been shown to affect [non-communicable diseases] NCD by influencing risk factors for [cardio-vascular disease] CVD such as obesity, diabetes, hypertension and dyslipidaemia. Infant nutrition (e.g. breastfeeding rather than bottle feeding) and a slower pattern of infant weight gain have been shown to be particularly protective against later risk of obesity and CVD in both low- and high-income countries."*[26]

Costs of breastfeeding

Breast feeding involves some initial costs also. These can include breast-feeding friendly clothes (eg a special bra), a breast pump and feeding bottles (if you want your partner or others to feed your baby also). You will also likely need extra food to satisfy your ongoing hunger as a breastfeeding mother.

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22 Romo-Palafox MJ, Pomeranz JL, Harris JL. *Infant formula and toddler milk marketing and caregiver's provision to young children*, **Matern Child Nutr**., 2020;16(3):e12962. doi:10.1111/mcn.12962, https://onlinelibrary.wiley.com/doi/full/10.1111/mcn.12962

23 Tariq S, Elford J, Tookey P, et al, 2016, *"It pains me because as a woman you have to breastfeed your baby": decision-making about infant feeding among African women living with HIV in the UK* **Sexually Transmitted Infections** 92:331-336, https://sti.bmj.com/content/92/5/331

24 Keshmiri R, Coyte PC, Laporte A, Sheth PM, Loutfy M., 2019, *Cost-effectiveness analysis of infant feeding modalities for virally suppressed mothers in Canada living with HIV*. **Medicine (Baltimore)**, 98(23):e15841. doi:10.1097/MD.0000000000015841 https://pubmed.ncbi.nlm.nih.gov/31169687/

25 National AIDS Trust, 2017, **Policy briefing: access to formula milk for mothers living with HIV in the UK**, https://www.nat.org.uk/sites/default/files/publications/Access%20to%20Formula%20Milk%20Briefing%20FINAL.pdf

26 Singhal A., 2016, *The role of infant nutrition in the global epidemic of non-communicable disease*. **Proc Nutr Soc**. 75(2):162-168. doi:10.1017/S0029665116000057

27 The term U=U is only used in relation to sexual transmission: see AIDSMAP, 2019, **What does undetectable = untransmittable (U=U) mean?** https://www.aidsmap.com/about-hiv/what-does-undetectable-untransmittable-uu-mean

Research and breastfeeding: U=U and breastfeeding

At the moment, U=U is only considered relevant to sexual transmission, since there is inadequate research and data for U=U to be considered applicable to breastfeeding[27]. However, researchers have provided guidance and recommend collaborative research to provide the missing evidence that enables women who wish to breastfeed their babies, make fully informed choices[28].

"Absence of evidence does not mean evidence of absence." Dr Shirin Heidari, Editor Journal of the International AIDS Society, 2010[29].

Peer support, both during and after birth

UNAIDS has recently highlighted ongoing challenges of HIV among children[30]. One factor identified was the importance of retaining women in care post-partum. In our view, perinatal peer support has a fundamental role to play in this process. The BHIVA guidelines recommend that *"pregnant women living with HIV are offered peer support where available"*[8].

COVID and infant feeding

We acknowledge BHIVA's statement that breastfeeding should be discouraged during COVID[9]. However, we feel strongly that, at a time when a woman's mental health is particularly vulnerable and any challenges to it are exacerbated by COVID, it is important not so much to emphasise a purely biomedical blanket policy. Instead we would prefer that BHIVA reflects full consideration for each individual woman's rights to choice and agency. We would therefore strongly recommend and prefer for BHIVA instead at this time to provide full accurate information about all feeding options, and to recommend that women should be trusted and supported to make their own informed choices about the best feeding options for their baby.

KEY RECOMMENDATIONS from the 4M Mentor Mothers Network

Right to Choice

Using the rights-based, women-centred and gender-equitable principle of the Consolidated Guideline on the SRHR of women living with HIV[2], it is important to recognise and acknowledge that some women living with HIV may wish to breastfeed. They need evidence-based, objective and non-judgmental information about risks, benefits and choices to enable them to make their own informed choices. Women's autonomy in decision-making must be respected to ensure that our SRHR are upheld. The more our rights are upheld, the more we will trust our healthcare providers and the more we are best-placed to look after ourselves, our babies and our older children.

"You can only make good choices and well-informed choices if you are given all the right non-judgmental info in the first place. In most cases women aren't getting this." Extract from Mentor Mothers' discussion about infant feeding

Full non-judgmental information

Healthcare providers should include the pros *and* cons of formula feeding, as well as the pros *and* cons of breastfeeding. Currently the emphasis is exclusively on the dangers of breastfeeding and reassurance about formula feed, purely looking at the very low risk of vertical HIV transmission. This imbalance

28 Waitt C, Low N, Van de Perre P, Lyons F, Loutfy M, Aebi-Popp K., 2018, *Does U=U for breastfeeding mothers and infants? Breast-feeding by mothers on effective treatment for HIV infection in high-income settings*. **Lancet HIV**, 5: e531–6, https://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018(18)30098-5/fulltext

29 Welbourn A, 2010, *Absence of Evidence does not mean evidence of absence*, **Open Democracy 50.50**, webpage, https://www.opendemocracy.net/en/5050/absence-of-evidence-does-not-mean-evidence-of-absence/

30 UNAIDS, 2020, **Progress towards the Start Free Stay Free AIDS Free targets**, https://www.unaids.org/sites/default/files/media_asset/start-free-stay-free-aids-free-2020-progress-report_en.pdf

needs to be addressed, so that women living with HIV are given the same information about formula feed that all other pregnant women are given. For example, women should be made aware of the additional time, financial cost, and planning ahead needed for safe and effective formula feeding, compared with the convenience, low cost and likely short and long-term health benefits of breastfeeding both for their baby and themselves.

"Blame in healthcare settings comes across very subtly but the women pick it up. You are told you will be supported but that's not the body language you will get. Women will still get blamed if the children have HIV. Women make [decisions with] the best intentions and you have to trust that this woman knows what she's doing and what's best for her child. But this isn't what's happening. If I give you half the information you will still go away thinking "I know what I'm doing" so what we are advocating for is to support them fully – say these are the options, so that you have a 360 degrees view and not just 180 degrees. You are only influencing their decision by giving them half the information." Extract from Mentor Mothers' discussion about infant feeding

"Whilst we were taught as students to focus on the bio-medicine, there is also much evidence to show that trusting women, listening to and respecting their preferences, can result in better long-term health outcomes – both for her and her child. It is vital women are provided with comprehensive and objective information in order to make their own informed choices about their lives. This is one area where physicians must shift the emphasis from the technical to where we know that good practice best lies." HIV obstetrician

Participation

Using the woman-centred principle of the Consolidated Guideline on the SRHR of women living with HIV, health services must view women as active participants in our own life and care and provide holistic services, based on women's priorities as equal partners in service design, implementation and review (see section 6 of the SRHR guidelines)[2,31,32].

Peer Support

Peer support, with the mentor mothers involved as part of clinic multi-disciplinary teams (MDTs) in clinic facilities with the flexibility of community outreach, is vital for women living with HIV. This will support women throughout the pregnancy journey and beyond, to stay on treatment, engage in care and safely breastfeed with dignity. Paid peer support and a professional pathway is essential, as volunteering is not sustainable.

Training

Ongoing trauma-informed training and implicit bias training of health and social care providers and workers in primary and secondary care is vital for practices that are supportive and positive for women.

"Healthcare settings are very judgmental. So often we hear women say: 'When we go to hospital we don't tell them what we are doing because they will tell us off'. Then health workers say to us that the women didn't tell them about such and such, but we say the women can't tell the health workers, because they are going to judge them. Clinics needs to understand that because of the way they are asking people things, people get scared off and don't tell them. We see this all the time with ARV adherence. Then you have a side conversation with the women and

31 Salamander Trust, 2020, **The WHAVE Podcast Paper #3. Equal partners: recognising the expertise of women living with HIV**, https://salamandertrust.net/wp-content/uploads/2020/04/20200506_The_WHAVE_paper3_PeerResearch.pdf

32 Anam F. et al., 2020, *How to include the perspectives of women living with HIV in research*, **BMJ Sexual and Reproductive Health**, blog, https://blogs.bmj.com/bmjsrh/2020/06/25/include-perspectives-hiv/

there are so many things going on for them. It's no wonder they can't adhere. You have the best of intentions and at the end of the day you are still blamed as a woman." ***Extract from Mentor Mothers' discussion about infant feeding***

Diversity

It is vital that healthcare professionals understand the difficulties women living with HIV can experience, especially those from migrant African communities where breastfeeding is a cultural norm. It is equally important that professionals have the education, physical and psychosocial support required to promote the women's wellbeing to carry on engaging in HIV care[18].

Team work

A multi-disciplinary team (MDT) approach, including financial assistance with replacement feeding, is vital for women to maintain their feeding decisions and reduce the emotional effects[8]. Other services may include peer support, psychological and practical support, and financial support for formula feeding.

"Having now supported more than 20 mothers living with HIV to breast feed and spending much more time discussing this option with others, I would say that I have found that by being more supportive to women when they are making a decision about infant feeding I have found a stronger bond with my patients who are then more likely to be comfortable being open with me and to continue to look after themselves." ***HIV Consultant***

Some perspectives of women living with HIV

One 4M Mentor Mother's perspective

"I breastfed my first 2 children and loved it. I was diagnosed with HIV when pregnant with my third child and as the midwife was telling me it was all a blur until she said I couldn't breastfeed, this felt like an arrow in my heart, that was when I started to cry. It was as if I could cope with all the prognosis she was telling me, but that was too much, that was when it felt real.

"After she was born, I had to lie, to everyone, I pretended I had mastitis, I felt dishonest. I found it difficult to do the bottles, mix it up correctly, I was so fearful. The early days when she was home I just felt out of my depth, having to hide medicine and doctors notes, all the deceit and secrecy that the health care workers conspired with me was so strange. Breastfeeding was something I was good at, it allowed a natural bonding, a sense of pride, completeness and I really missed it. At a time when I was feeling worthless because of the virus, feeling contagious, infected, unlovable, adding not being able to feed my baby perpetuated that, it was like there was nothing I could do, I wasn't a 'proper' mother, so that even just changing nappies I started to self-doubt, question if I was doing it right!

"If I had had support, like a mentor mother and been aware of these new guidelines I believe I would have still used formula. It would have been my choice, and that I think would have made all the difference, I would have been in control and that would have given me a sense of purpose, I would have been doing what I felt was best, rather than feeling useless." ***4M Mentor Mother.***

One lady who did want to breastfeed but was advised not to:

"A lady I am supporting recently wanted to breastfeed and was persuaded by her health workers not to. She is still trying to come to terms with it and has good and bad days particularly as this is her first child and it is something she so wanted to do. It is such a shame when the guidelines now state that if a woman wants to, her health providers should support her to do so. I am now having to support her around how to manage the situation with her family who are keen to know why she is not breastfeeding and this is causing her a great deal of anxiety as her HIV status is something she wishes to keep private" ***4M Mentor Mother***

Quotes from 4M Mentees who did breastfeed

"Dr Edward Back in 1996 said 'Ignorance is the failure to learn, the refusal to see Truth when the opportunity is offered' and Olivia Ndoti in 2020 said, 'If we refuse to acknowledge our own existence because of illnesses, we are only damaging our immune system that connects with the mind, body and soul.' If I had never listened to my doctor's advice, medical advice from different health sectors and researching about my condition, I would have not been able to breast feed my son for six months. You can not go alone on the path of a chronic illness" ***4M Mentee***

"I am supporting a woman who has just had her fourth child. She has now felt ready to breastfeed for the first time and it is so special for her to feel fulfilled as a woman to have this experience also. It has been a real journey for her and because she is getting the right support from her multi-disciplinary team she is now able to do this....."
4M Mentor Mother

Other high-income country experiences

A US-based study assessed the evidence and ethical justification for current policy. It paid attention to pertinent racial and health disparities and reviewed maternal health considerations. This study found that current guidelines which advocate that women living with HIV should avoid breastfeeding may not necessarily maximize health outcomes. As a consequence, the authors recommend a 'harm reduction' approach and a revision of their national guidelines[33].

A more recent paper, reviewing both US and UK policies, entitled "Moving Closer to What Women Want?" came to a similar conclusion[34].

An online wide-ranging article from the Well Project in the US in June 2020 states: *"While research into this issue continues, it is important for care providers and other community health professionals to help women make informed choices based on the information we have today, and to provide support to those who choose to breastfeed their babies."*[13]

In addition, a recent interview conducted by the Well Project with Hannah O'Connor, who describes her own breastfeeding experiences, is a very informative read[35].

33 Gross MS et al., 2019, *Breastfeeding with HIV: An Evidence-Based Case for New Policy*, **J Law Med Ethics**, 47(1):152-160. doi:10.1177/1073110519840495, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7053566/

34 Freeman-Romilly, N., Nyatsanza, F., Namiba, A. and Lyall, H. (2020), *Moving closer to what women want? A review of breastfeeding and women living with HIV in the UK and high-income countries*. **HIV Med, 21: 1-8**. https://onlinelibrary.wiley.com/doi/full/10.1111/hiv.12792

35 The Well Project, 2020, **Spotlight on Heather O'Connor: My Journey with Breastfeeding and HIV** https://www.thewellproject.org/hiv-information/spotlight-heather-oconnor-my-journey-breastfeeding-and-hiv

Conclusion

We hope that this policy statement will support healthcare workers and women living with HIV alike to move yet closer to what women really want, based on non-judgmental fully informed, choice; and full support for whatever each woman decides for herself, for each pregnancy, whatever the long-term outcomes may be, both for herself and for each of her children.

Deciding what route to take with infant feeding is only the first step. All infant feeding, whichever form it takes, can be stressful to begin with, especially for first-time mothers. Whatever each woman decides for herself, she needs full ongoing support from all those around her, so that she feels confident to do what she feels is best for her baby, and so that she and those around her can access the guidance, reassurance and practical support that she needs to maximise her experience of childbirth as a positive, life-enriching experience for herself as well as her baby. 4M Mentor Mothers Network will be looking shortly at practical next steps to take, to strengthen support for the mentees in their care around all infant feeding practices.

There are so many things going on for [women]. It's no wonder they can't adhere. You have the best of intentions and at the end of the day you are still blamed as a woman

Women advised not to breastfeed for their baby's health should be provided with free formula feed to minimise vertical transmission of HIV

If I had had support, like a mentor mother and been aware of these new guidelines I believe I would have still used formula. It would have been my choice, and that I think would have made all the difference, I would have been in control and that would have given me a sense of purpose, I would have been doing what I felt was best, rather than feeling useless.

DISCLAIMER: this policy brief reflects the collective views of members of 4M Mentor Mothers Network CIC. If you are a woman living with HIV in the UK considering breastfeeding, please consult your relevant health care advisers. You can also contact us at info@4mmm. org if you would like to discuss your plans with us. These views do not necessarily reflect the views of all the members of our 4M Steering Group.

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